Representations of Endometriosis in the Popular Press: "The Career Woman's Disease"

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ABSTRACT

This study explores how endometriosis is represented in the popular press. Content analysis of sixty-four magazine articles published between 1975 and 2001 was conducted. Common themes appearing in magazine articles were examined. Results indicate the popular press represents endometriosis primarily as a fertility problem. Improvements in media coverage of endometriosis are recommended.

RÉSUMÉ

Cet article explore la façon dont la presse populaire représente l'endométriose. Une étude de l'analyse de soixante-quatre articles de revues a été menée. Les thèmes communs qui apparaissent dans les revues ont été étudiés. Les résultats indiquent que la presse populaire représente l'endométriose principalement en tant qu'un problème de fertilité. L'article recommande que les médias améliorent la façon dont ils couvrent l'endométriose.

INTRODUCTION

The concept of medicalization describes the process that takes place when normal conditions are defined in terms of health and illness, thereby making normal behaviors or conditions undesirable. Medical practice becomes the "vehicle for eliminating or controlling problematic experiences that are defined as deviant, for the purpose of securing adherence to social norms" (Riessman 1983, 4). Riessman argues that normal events in women's lives, such as childbirth, childlessness, menstruation, and menopause, have been medicalized, and she suggests endometriosis represents another new disease construction. I will argue that endometriosis-related infertility, rather than endometriosis, is defined in the medical and popular literature as a disease requiring medical treatment.

Endometriosis is defined in the medical literature as a disease affecting women in their reproductive years. It occurs when the tissue that normally lines the uterus grows in other parts of the body, such as the ovaries, the lining of the pelvic cavity, or the fallopian tubes. Endometrial tissue outside the uterus has no way of leaving the body, and thus, endometriosis results in internal bleeding, inflammation of the surrounding areas, and formation of scar tissue. According to the medical literature, symptoms of endometriosis include pain before and during menstruation, pain during or after sexual activity, infertility, and heavy or irregular bleeding. Diagnosis of endometriosis is considered uncertain until confirmed by laparoscopy, a surgical procedure in which a laparoscope (a tube with a light in it) is inserted into a

tiny incision in the abdomen. Carbon dioxide is used to expand the abdomen so that the surgeon can check the condition of the abdominal organs and see endometrial implants. It can be difficult to diagnose endometriosis in women, even using laparoscopy, because some endometrial implants can be too tiny to be viewed via laparoscope. It has been reported that approximately five and a half million girls and women in Canada and the United States are affected by endometriosis (Berger 1993).

ENDOMETRIOSIS IN THE MEDICAL LITERATURE

The medical literature on endometriosis can be divided into two broad categories: clinical reports and health research. Prior to the widespread use of laparoscopy as a diagnostic technique, clinical discussion featured such issues as the etiology and histogenesis of endometriosis, diagnosis, medical and surgical treatments, the relationship between endometriosis and infertility, and epidemiological factors such as race and class (Aimakhu and Osunkoya 1971; Kistner 1959; Weed 1955). Early clinical reports suggested a certain type of woman was prone to endometriosis:

> Two types of patients have endometriosis; those who are normal in every way except that marriage and pregnancy are delayed, and those who have a stigma of pelvic underdevelopment...It is therefore better that there be earlier marriages and that

contraception be put off until at least one or two pregnancies have occurred. What is more pathetic than the girl who marries and for economic reasons can't have a baby, who later goes to her doctor with a sterility problem that cannot be solved? (Meigs 1938, 254)

The notion that women who delay marriage and pregnancy develop endometriosis has persisted in the clinical literature, earning the disease the nickname "the career woman's disease" in medical textbooks (Darrow et al. 1994). This suggests doctors believe women in our society exist primarily to be wives and mothers. Clinical reports have continued to foster the idea that career women develop endometriosis, instead of disputing this sexist, outdated notion.

Recent clinical reports focus on a variety of issues including histogenesis, epidemiology, diagnosis, symptoms of pain and infertility, medical and surgical treatments, and recurrence of endometriosis after treatment (Child and Tan 2001; Cramer and Missmer 2002; Lessey 2000; Murphy 2002; Olive and Pritts 2002; Witz and Burns 2002). Clinicians also debate particular issues such as whether endometriosis is actually a disease, what patients with endometriosis expect from their doctors, and the approaches and perspectives of doctors on the treatment and management of endometriosis (Brosens 1997; Evers 1994; Jones 1988; Miller and Rebar 1988). Recent clinical research has focused on the relationship between endometriosis and toxic chemicals called dioxins found in air, food, and tampons, as well as the possibility that endometriosis is an autoimmune disease (Eskenazi et al. 2002; Nothnick 2001; Rier 2002; Scialli 2001).

In contrast, health researchers have focused on such epidemiological factors of endometriosis as age. race, class, fertility patterns, reproductive factors, and familial factors (Arumugam and Templeton 1992; Arumugam and Welluppilai 1993; Cavanagh 1951; Chatman 1976; Chatman and Ward 1982; Darrow et al. 1994; Matorras et al. 1995; Miyazawa 1976; Moen and Magnus 1993; Osefo and Okeke 1989; Scott and Te Linde 1950). Recent health research has also examined the notion that endometriosis is "the career woman's disease." Researchers investigated sexual activity, contraception, and reproductive factors in predicting endometriosis. They concluded that their results did not support "simplistic assumptions" that characterized women with endometriosis as career women. Instead, they found a complex relationship between endometriosis, sexual activity, and fertility-related factors (Darrow et al. 1994).

Health research on endometriosis also features psychosocial studies examining the relationship between mood disorders and endometriosis, the

involvement of personality in the expression of pain, and the relationship between women's symptoms of endometriosis and self-esteem (Christian 1993; Gomibuchi et al. 1993; Lewis et al. 1987; Low et al. 1993; Walker 1989; Waller and Shaw 1995). These psychosocial studies blame women with endometriosis for the development of their "mysterious" symptoms and disease (Ballweg 1997). The use of a new endometriosis quality-of-life survey instrument, the Endometriosis Health Profile-30, should enable clinicians and researchers to get a better understanding of the effects of endometriosis on women's lives (Jones et al. 2001). Perhaps such a research tool will help eliminate the sexist attitudes displayed by some doctors and health researchers towards women with endometriosis.

The medical literature about endometriosis defines it primarily as a fertility disease, focusing on how medicine can help women avoid endometriosis-associated infertility. Clinicians and health researchers rarely focus on the problem of the physical pain which endometriosis causes in women's everyday lives. Instead, clinicians and health researchers usually focus on the "problem" that infertility causes in women's lives, generally recommending early marriage and pregnancy to avoid endometriosis-related infertility. In that regard, Riessman suggests that "physicians create and reinforce social norms when they define behaviors or conditions as pathological, such as... childlessness in women" (1983, 5); women are supposed to have babies, and therefore, medical doctors and researchers consider it a problem if women are unable to have children due to endometriosis. On this, Shohat has concluded that, "Medical writing has clearly theorized endometriosis in terms of disorderly female biology, behavior, and personality" (1992, 60).

If endometriosis is defined in the medical literature as an infertility disease, how is endometriosis portrayed in the popular press? Feminist scholars have argued that we live in a patriarchal culture in which men create ideology, knowledge, and culture based upon their own experiences (Smith 1987; Walby 1990). Smith contends that "The relations of ruling have a strongly gendered character. Power...has come to mean for men the entry into...a technical or scientific world of the expansion of systematic knowledges" (213). Women were traditionally excluded from this scientific world. and therefore, men have been allowed to define public knowledge about endometriosis in published medical reports. It is important to determine how these definitions are treated by the popular press, since many women use the popular press as a source of health information.

METHODOLOGY

Researchers conduct content analysis by systematically counting or interpreting themes within a set of objects, cultural artifacts, or events (Reinharz 1992). Content analysis has proven to be a useful technique for evaluating print materials and has frequently been used to examine the popular press. Several studies have been conducted to determine the general content of women's health issues published in women's magazines in the United States and Great Britain (Elliot 1994; Lepley 1991; Martinez et al. 2000; Weston and Ruggiero 1985). Recently, researchers have explored menstruation, premenstrual syndrome, and postpartum mood disturbances by interpreting themes in magazines, magazine articles, and advertisements (Chrisler and Levy 1990; Coutts and Berg 1993; Markens, 1996; Martinez et al. 2000; Pugliesi 1992). No one, however, has studied the representation of endometriosis in popular magazines.

For this study, I attempted to identify all articles about endometriosis published in Canadian and American magazines between 1975 and 2001. The Reader's Guide to Periodical Literature was used to locate sixty-four magazine articles on endometriosis. Magazines such as Chatelaine, Flare, Mademoiselle, and Glamour are classified as women's magazines because they contain advice specifically for women on topics such as fashion, beauty, and health. News magazines such as Maclean's and Newsweek report recent newsworthy events. Health and fitness magazines such as American Health, Women's Sports and Fitness, and Prevention, on the other hand, focus on issues related to health and fitness. Finally, magazines such as Healthsharing, Ms., and Herizons are classified as feminist magazines because they analyze a variety of women's issues from feminist perspectives.

A review of magazine articles about endometriosis was conducted and the following question was addressed: How is endometriosis represented in the popular press? Magazine categories, titles, number of articles, and publication years were determined for the articles published in popular magazines. Articles were selected if they were at least two paragraphs in length and if the main focus of the article was endometriosis. Publication years of articles were compared to determine whether any trends were apparent. Themes appearing in the popular press were systematically counted, coded, and percentages were calculated, where possible, to determine the frequency of these themes.

RESEARCH FINDINGS

Articles in popular magazines usually followed the medical model of endometriosis prevalent

in the medical literature. Medical doctors were treated as endometriosis experts and they were quoted extensively throughout the articles. Key themes included misdiagnosis, symptoms, medical and alternative treatments, and women's stories of living with endometriosis.

Women's magazines, feminist magazines, and news magazines reported that misdiagnosis of endometriosis was common. In Western Report, Rooney (1989) suggests that women with endometriosis are often misdiagnosed as having psychosomatic disorders. Feminist magazines and women's magazines referred to medical research indicating racism in the diagnosis of endometriosis. In Healthsharing, a feminist publication, Williams (1993a) reported the results of a medical study in which it was found that, "as many as 40 percent of African American women are misdiagnosed as having a sexually transmitted pelvic inflammatory disease (PID) when in fact they suffer from endometriosis" (9). In a recent women's magazine, Kashef (1996) reported that, "African-American women in particular may be at risk of being misdiagnosed because of a long-standing misconception that only white middle-class women get the disease" (32).

One article published in *McCall's* warned women to beware of doctors who over-diagnose endometriosis (Nolen 1981). In all types of magazines, women's stories of endometriosis did not reflect this phenomenon. Williams (1994, 42) reported that the use of laparoscopy has "resulted in the discovery of thousands of previously undiagnosed cases of endometriosis," providing medical confirmation of the pain that many women had been told they were imagining. The title of an article in *New Woman* sums up this issue: "The Diagnosis Doctors Miss Most."

Popular magazines also addressed the symptoms of endometriosis. The two most common symptoms of endometriosis recounted in the popular press are pain and infertility. Articles in women's magazines, news magazines, and health and fitness magazines featured the symptom of infertility. Titles of articles, subtitles, and section headings in the magazines emphasized a connection between endometriosis and infertility: "Can't Get Pregnant?"; "Endometriosis: a Growing Cause of Infertility in Women"; "The Baby Blues: How Late Should You Wait to Have a Child?"; "Endometriosis Is a Common Cause of Infertility in Women"; "Endometriosis: the New Young Women's Infertility Disease"; and "They Said I Couldn't Have a Baby."

Several of the articles in women's magazines focusing on infertility were particularly frightening. For instance, one article published in *Mademoiselle* describes endometriosis as "one of the scariest health problems facing many young women today...it is a 'silent' [disease] that can rob them of their fertility" (Morice 1987, 94). It was also assumed by most reporters that all women want to bear children and, therefore, they must be concerned with preserving their fertility. For example, Cherry (1991, 184) advises women that if endometriosis is diagnosed early, it can be treated "before you experience any symptoms and can be prevented from spreading, thus preserving your ability to conceive a child." A recent article in a women's magazine states that doctors may tell women with endometriosis to get pregnant right away, but if a woman isn't ready to get pregnant, "she should be assertive with her doctor about pursuing other treatments" (Cool 1999, 100).

Popular magazine articles promoted the notion that endometriosis and infertility were more likely to occur in ambitious career women, an idea that originated in the medical literature. This notion stems from the belief of medical doctors that if a woman with endometriosis delays childbearing in favour of her career, then her chances of becoming pregnant may decrease. The idea that there is an endometriosis-prone personality is encompassed in the concept of "the career woman's disease." Women with endometriosis were reported to be ambitious career women with demanding jobs (Gray 1981; Norwood 1985; Smith 1979; Vanderhaeghe 2000; Zimmerman 1975). Articles published in women's magazines, news magazines, health and fitness magazines, and feminist magazines focused on the notion that endometriosis is "the career woman's disease." Despite the fact that medical research has proven that career women are not prone to endometriosis, the popular press continues to relate women's careers to endometriosis.

In a recent issue of *Total Health*, Vanderhaeghe states that, "Working women are the most vulnerable to endometriosis" (2000, 36). Vanderhaeghe cites Tori Hudson's book *Women's Encyclopedia of Natural Medicine* as her information source, but it is obvious Vanderhaege did not read very carefully since, in fact, Hudson wrote: "Early research as to the source of infertility initially led to the concept that endometriosis was a 'working woman's disease.' Current research does not support this concept" (1999, 79). Unfortunately, the popular press continues to perpetuate the myth of endometriosis as "the career woman's disease."

Popular magazines also discussed medical and surgical treatments of endometriosis. There were, however, significant differences in the kinds of information women received from different types of magazines about the medical treatments of endometriosis. For instance, health and fitness magazines and feminist magazines offered women more detailed and more accurate information about the medical treatments of endometriosis compared to articles in news magazines and women's magazines. In reports about the side effects of various medical treatments for endometriosis, for example, health and fitness magazines such as Vegetarian Times and feminist magazines such as Healthsharing were more candid than women's magazines and news magazines. They included descriptions of possible side effects and the experiences of women who suffered side effects of medical treatments. When side effects of medical treatments were presented in women's magazines and news magazines, however, they were often minimized and readers were not informed of women's experiences with these treatments. Moreover, news magazines such as Time and Newsweek only published short articles when a new medical or surgical treatment was available, whereas women's magazines, health and fitness magazines and feminist magazines all reported on treatments in conjunction with other aspects of endometriosis. The popular press presented medical treatments as a way to ameliorate endometriosis-associated infertility - see Table 1.

Popular magazine articles I examined also focused on alternative therapies. Alternative therapies suggested in these articles included diet and nutrition, acupuncture, herbs, homeopathy, visualization, relaxation, massage, reflexology, and exercise. Feminist magazines and health and fitness magazines, for example, investigated the use of alternatives to medical treatments for pain relief and healing. Reporters argued that women could heal themselves by using alternative therapies and maintaining a healthy lifestyle. Valverde suggested, for example, that "self-healing might mean changes in living and eating habits, as opposed to taking a prescribed drug" (1981 14). Challem and Lewin (1989), on the other hand, recommended certain vitamins and minerals that could reduce the amount of estrogen in women's bodies, thereby relieving symptoms of endometriosis. One woman reported she healed her endometriosis through the self-prescribed use of vitamin and mineral supplements (Karnes 1979). More recently, women's magazines began discussing the utility of alternative therapies for women with endometriosis (Cool 1999; Kashef 1996). Again the focus was on solving the problem of infertility related to endometriosis.

Women's stories were scattered throughout articles about endometriosis in the popular magazines. Women's magazines focusing on women's stories of dealing with endometriosis usually emphasized the threat of infertility, women's desire to have children, and the grief that women experience as a result of their infertility (*Good Housekeeping* 1980; Pogash 1982; Smith 1986). Pogash, for instance, reported that she "was willing to undergo anything to have a baby" (82), and Smith felt she had been "attacked and savaged in the most fundamental and frightening way a woman can be. I had been told that I was no longer a woman" (126). In contrast to women's magazines, women's stories of living with endometriosis recorded in feminist magazines, news magazines, and health and fitness magazines emphasized medical treatments and alternative therapies. Only the feminist magazines conveyed women's experiences of paternalism and sexism in the medical sphere. Latta (1988) reported in *Healthsharing* magazine that she encountered paternalism in her relationships with two doctors.

Feminist magazines and women's magazines reported that women with endometriosis often felt frustrated, angry, and humiliated because they suffered for a long time before they were diagnosed with endometriosis. In that regard, Pogash stated that, "one insensitive doctor suggested that my problem might be that I really didn't want to become pregnant, a remark that infuriated me" (1982, 84). Wilcox reported women were angry and frustrated because they suffered from a disease that "has been for so long ignored, mistreated and misunderstood simply because it is a woman's disease" (1990, 129).

DISCUSSION

Popular magazines defined endometriosis according to the existing medical model. Issues such as obtaining a diagnosis of endometriosis, symptoms of pain and infertility, and medical, surgical, and alternative treatments of endometriosis were the focus of magazine articles. All of these issues are linked to the medical "problem" of endometriosis-associated infertility. Little attention is given to the fact that some women do not want children, and for those women who do want children, adoption is a real option. Shohat contended that, "in the context of the feminist movement, endometriosis has often been referred to as the 'career woman's disease' because of its enduring association with the choice not to bear children" (1992, 65). Instead, the popular press, like the medical literature, focuses on the need to fix women's bodies so they can bear children. Women's stories found in popular magazines mostly reflect the views of women who define endometriosis as a fertility disease. Moreover, the medical and popular literature is such that "upper-middle-class white women are diagnosed with a career-related disease" while black women are diagnosed with a sexually transmitted disease (Shohat 1992, 68).

Despite an emphasis on infertility, representations of endometriosis in the popular press have changed in the last decade. Recent articles about endometriosis found in the popular press describe the disease as an epidemic, recognizing the large numbers of women with the disease. Women's magazines and health and fitness magazines recently reported news of medical research into the causes of endometriosis, citing studies that link dioxins with endometriosis and indicate that endometriosis may be an autoimmune disease. Mainstream popular magazines have recently begun to address political issues related to the diagnosis and treatment of endometriosis. Anthony (1996) reported in *American Health* that government funds to support endometriosis research have been scarce because the disease only affects women. Nevertheless, the popular press continues to emphasize endometriosis-related infertility and to perpetuate the myth that endometriosis is somehow related to women's careers.

The feminist press offers a more balanced look at endometriosis. Feminist magazines such as *Healthsharing, Herizons,* and *Waterlily* addressed issues ignored by the other magazines, such as women's need for accurate information about endometriosis and support groups. Articles in feminist magazines have always focused on how women could be empowered in order to cope with their endometriosis, while women's magazines have only recently addressed this issue. Most importantly, feminist magazines offer information about infertility without the scare tactics used in the mainstream media.

CONCLUSION

Media coverage of endometriosis plays an important role in shaping public discourse on the topic. Medical experts and the popular press define endometriosis as a fertility disease requiring medical intervention. Major problems with the coverage of endometriosis by the popular press are the emphasis on infertility, the limited perspective, and the perpetuation of sexism. Recommendations to improve media coverage of endometriosis include:

a) Health researchers must provide reporters with accurate and non-sexist information about endometriosis, and they should dispel the myth of "the career woman's disease."

b) Journalists should always refer to the most recent medical and health research about endometriosis because researchers continue to find and report new information about the disease. The Endometriosis Association is also a good source of current, accurate, and non-sexist information.

c) Journalists and editors must question information obtained from doctors and outdated medical literature. They must become familiar with the recent medical literature, which dispels paternalistic and sexist notions such as that of "the career woman's disease."

d) Journalists and editors should refrain from using scare tactics when it comes to the issue of infertility. The method used to address infertility could be modified to include information on how to accept infertility, for example, by adopting children or living childless.

In sum, endometriosis is represented in the medical and popular literature as a frightening disease causing infertility in women. Furthermore, women in our society have been blamed in the medical and popular literature for contracting endometriosis by delaying childbirth and pursuing careers. Women seeking information about endometriosis may be alarmed by the information they find in the popular press. Coverage of endometriosis in the popular press must eliminate outdated sexist notions and provide women with current and accurate information.

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Table 1

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Category Title Number of articles Total and publication years Women's Canadian Living 1 (1990) 28 Magazines Chatelaine 1 (1985) (n=17) Cosmopolitan 1 (1994) Flare 2 (1987; 1993) Essence 1 (1996) Glamour 2 (1990; 1991) Good Housekeeping 2 (1980; 1987) Harper's Bazaar 1 (1999) Ladies' Home Journal 1 (1975) Mademoiselle 4 (1978; 1985; 1987; 1999) McCall's 4 (1981; 1985; 1987; 1989) New Woman 1 (1999) Parents 1 (1991) People Weekly 1 (1985) Redbook 3 (1982; 1986; 2000) Verve 1 (1987) Working Woman 1 (1979) Feminist Magazines Healthsharing 7 (1981; 1988; 1990; 1991; 1993) 12 (n=4) Herizons 1 (1994) Ms. 2 (1981; 1995) Waterlily 2 (1990) News Magazines Maclean's 3 (1982; 1988; 1989) 6 (n=4)Newsweek 1 (1986) Time 1 (1986) Western Report 1 (1989) Health and Fitness American Health 2 (1988; 1996) 18 Magazines FDA Consumer 1 (1986) (n=11)Health 2 (1986; 1988) Health News 2 (1993; 2001) Let's Live 2 (1989; 1992) Prevention 3 (1979; 1987; 1990) Today's Health 2 (1987: 1990) Total Health 1 (2000) Vegetarian Times 2 (1992; 2001) Women's Sports and Fitness 1 (1986) 64

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